

Members

Sen. Kent Adams, Chairperson
Sen. Marvin Riegsecker
Sen. Allie Craycraft
Sen. Connie Sipes
Rep. Vanessa Summers
Rep. Dennie Oxley
Rep. Robert Alderman
Rep. Cleo Duncan
Hugh Beebe
Nan Daley
Michael Carmin
Herb Grulke
Donna Ott
Becky Zaseck



INDIANA COMMISSION ON AUTISM

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MEETING MINUTES¹

Meeting Date: October 4, 1999
Meeting Time: 10:30 A.M.
Meeting Place: State House, 200 W. Washington
St., Room 233
Meeting City: Indianapolis, Indiana
Meeting Number: 1

Members Present: Sen. Kent Adams, Chairperson; Sen. Allie Craycraft; Rep. Vanessa Summers; Rep. Dennie Oxley; Rep. Robert Alderman; Rep. Cleo Duncan; Hugh Beebe; Nan Daley; Michael Carmin; Herb Grulke; Donna Ott; Becky Zaseck.

Members Absent: Sen. Marvin Riegsecker; Sen. Connie Sipes.

Senator Adams called the meeting to order at 10:35 AM and asked the members and staff of the Commission to introduce themselves.

1999 Legislation

Rep. Summers stated that there were two bills containing autism-related issues that passed during the 1999 legislative session. The first was inclusion of autism concerns about waiver waiting lists in 1999 legislation concerning developmentally disabled individuals. The second was HEA 1095-99 which included autism in the group of

¹ Exhibits and other materials referenced in these minutes can be inspected and copied in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for copies may be mailed to the Legislative Information Center, Legislative Services Agency, 200 West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for copies. These minutes are also available on the Internet at the General Assembly homepage. The URL address of the General Assembly homepage is <http://www.ai.org/legislative/>. No fee is charged for viewing, downloading, or printing minutes from the Internet.

diagnoses for which individuals can obtain services under the Children with Special Health Care Needs program.

Rep. Summers discussed bills introduced during the 1999 session that did not pass. Included in this discussion were bills regarding: (1) insurance coverage for autism; (2) certification of group homes; (3) development of additional group homes; and (4) nonreversion of funds in the developmentally disabled client services account.

There was general discussion regarding the nonreversion issue and it was agreed that this issue should be reconsidered during the 2000 legislative session. Commission members discussed the issue of certification of residential settings for developmentally disabled individuals. Mr. Grulke stated that this issue was not stressed during the 1999 session because state agencies are currently working on updating certification programs.

Ms. Daley suggested that the Commission consider reintroduction of the contents of HB 1543-1999 regarding quality assurance of services for developmentally disabled individuals.

Rep. Alderman raised the issue of the Family and Social Services Administration's (FSSA) approach to services for developmentally disabled individuals. He stressed that new group homes do not seem to be part of the approach and that there should be follow-up to account for deinstitutionalized individuals. There was general discussion among the members regarding group homes, which provide caregivers, versus groups of people living together without caregivers. Lauren Polite, Legislative Liaison, FSSA, stated that she would like to bring Debbie Wilson, Director of Disability, Aging, and Rehabilitative Services, FSSA, to a future meeting to discuss group homes and FSSA's approach to services for developmentally disabled individuals.

Sue Lindborg, Cristole, Inc., stressed her view that there should be increased focus on children's issues in thinking about group homes. Rep. Summers agreed that children and adults should be treated differently due to different needs. Ms. Daley explained that autism is a spectrum disease and that there is a wide spectrum of services that work for individuals with autism. She stated that there need to be choices for families of children with autism so that each child's specific needs may be met.

Waiver Update

Walter Thomas, Division of Disability, Aging, and Rehabilitative Services, FSSA, provided a handout reflecting current information regarding the autism waiver (See Exhibit 1). Mr. Thomas acknowledged that the sooner a child with autism can receive services provided under the autism waiver, the better chance the child has to reach the child's potential. He pointed out that there are now 202 individuals on the autism waiver, which is 2 more than the goal of 200. He explained that the number covered under the waiver can be increased by 50 slots per year up to 400 slots. Mr. Thomas gave approximate costs for individuals on the waiver with an average cost of approximately \$2892.00 per month.

Rep. Summers asked about how the "317" monies and the autism waiver work together. Mr. Grulke stated that compromises during the 1999 session resulted in 100 slots allocated for the ICF/MR waiver. Commission members questioned whether these slots would be filled with individuals with autism.

Mr. Thomas discussed various methods that are used to increase awareness in the community of waiver services including handouts, training, and communications with providers.

Capt. Carmin asked about the waiting time to be placed on the autism waiver once a slot is

open. Mr. Thomas responded that the average time is approximately 54 days, depending on how quickly information that is needed to place an individual on the waiver is returned. Mr. Thomas explained that the time that an individual is on the waiting list before a slot opens may be up to 4 years. He stated that there are currently 730 people on the autism waiver waiting list.

Rep. Alderman and Rep. Summers asked that Ms. Wilson explain at a future meeting how the "317" money is being utilized. In response to a question from Sen. Craycraft, Mr. Thomas stated that the autism waiting list increases in length every week.

Preschool Intervention Programs

Karen Mummery, Parent, Crown Point, Indiana, provided a handout of her testimony (See Exhibit 2) and discussed her experiences in obtaining services for her daughter. She discussed her concerns with the lack of programs of treatment for preschool children in Indiana. Ms. Mummery described the Wisconsin Early Autism Program (WEAP) that she is using for her daughter and the progress that her daughter has made in the short time that she has been using WEAP. She advocated that special education teachers who teach autistic children be required to have an autistic impaired endorsement.

Ms. Daley shared her experiences in obtaining services for her son. She expressed her belief that increased resources are needed in Indiana. She stated that the best intervention for a child with autism is education.

Sen. Sue Landske provided information regarding a constituent's experiences with services in Indiana, and with the Giant Steps program from Montreal, Canada. Sen. Landske stated that she will travel to Montreal with a group of Indiana legislators to see the program in the next few weeks. There was discussion that the Giant Steps program is for older children and that it is important to provide appropriate services within the window of opportunity, believed to be between 3 and 6 years of age, for autistic children. Commission members discussed asking Cathy Pratt, Indiana Resource Center for Autism, and Bob Marra, Indiana Department of Education, to discuss replication in Indiana of programs currently in place in surrounding states.

Andrea Kellar, parent, Northwest Indiana, presented a handout of her testimony (See Exhibit 3) and discussed her experiences with her son. She stressed the window of opportunity during which treatment is most advantageous and asked for better educational standards and assistance in funding of early intervention programs.

Leslie Dziezak, parent, Northwest Indiana, presented a handout of her testimony (See Exhibit 4) and related her experience with her son. She stated that her family is considering moving from Indiana to another state to obtain financial assistance in providing services to her son.

Jill McNeil, parent, Highland, Indiana, presented a handout (See Exhibit 5) and shared her experiences with her son. Ms. McNeil stated that she is aware of families moving to Wisconsin to obtain assistance. She explained that waiver monies cannot be used for programs for her son because waiver monies cannot legally be used for education. Ms. McNeil stressed that programs that teach autistic children how to function and how to learn are needed in Indiana.

Ann Collins, grandparent, Northwest Indiana, related the experience of her children in obtaining services for her two autistic grandchildren. She stressed the need for autistic children to learn communication skills and for the schools to participate in programs for autistic children. She suggested a model program to determine the best method of providing services in Indiana. Ms. Collins referred to South Carolina's "TEACH" program

which has been in place since the 1970's.

Korryn Fairman, FSSA , explained that waiver funds, under federal law, cannot be used to fund educational services. She stated that the funds can be used to pay for therapies.

Sen. Adams set the next meeting for Monday, October 18, 1999 and adjourned the meeting at approximately 1:30 PM.